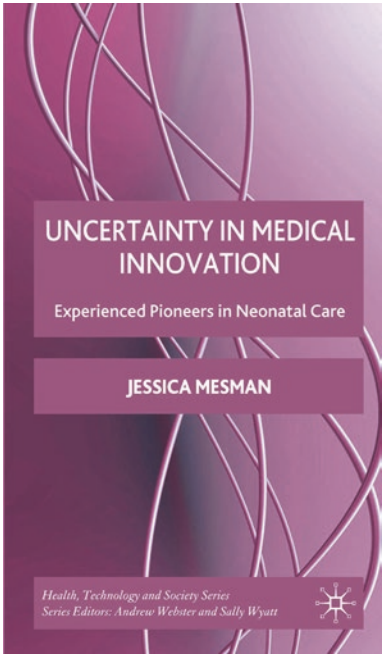
Uncertainty in Medical Innovation

Jessica Mesman. (2008). *Uncertainty in Medical Innovation. Experienced Pioneers in Neonatal Care*. Winner of Foundation for the Sociology of Health and Illness Book Prize 2009



From: Chapter 1, Neonatology: A Permanent Dynamic of Change, pp. 1–2, 4–7

Academic Medical Center:

Bleeping monitors, toiling ventilators, and alarm signals all around. As the door swings open, an incubator rocks over the threshold, flanked by a nurse and a resident. In the incubator Tom is lying amidst lines and tubes, barely fifteen minutes old. He was born prematurely at twenty-five weeks' gestation; his weight of 610 grams sharply contrasts with the average 3500 grams of full-term newborns. Skilled hands carefully take him out of the

incubator and put him into his own bed: an incubator surrounded by an array of medical devices. His twin brother died right after the delivery.

Fed, warmed, and on a respirator: thus Tom's life begins. Tiny and vulnerable, he is immediately taken to the intensive care unit of the hospital's neonatology ward. The neonatology ward specializes in the care and treatment of newborns, also called neonates [a baby of no more than 28 days]. As a rule, children born after a term of less than 32 weeks or with a birth weight under 1000 grams are always admitted to this ward. […]

A NICU leaves first-time visitors with an impression of controlled chaos—an amalgam of busy staff, noisy machinery, and a strange sense of order. Newborn babies are here because their lives are seriously at risk on account of complications linked to their delivery, congenital diseases, infections, or premature birth. Lined up, side-by-side, the incubators are connected to an array of state-of-the-art medical technologies with all sorts of tubes and cables: monitors that display flickering numbers and respirators that rhythmically do what they were designed to do until they suddenly generate a bubbling sound or piercing rattle. Most babies are sleeping all day and night, most with the help of sedatives. A single baby may be crying—without making a sound, on account of the respirator tube in the throat. The fragility of the children calls for their constant monitoring. After all, these are the children who do not always respond to medical interventions according to the descriptions found in handbooks, while factual data on their conditions are ambiguous or not available yet. This also explains the round-the-clock presence of nurses and physicians in a NICU. One sees them engrossed in their work of caring for their very young and fragile guests. Much of the medical work involved centres on generating and keeping track of patients' vitals, recording new data, or checking and rechecking them. The calm, soft-spoken interactions of nurses and doctors rely on a vocabulary that seems specially invented for this space. Parents too have a prominent presence. Regardless of the time of day or night, some are found sitting for hours at the side of the incubator containing their newborn baby. Clearly, then, the lights in the NICU are never turned off.

…

This book provides insights into the concrete work setting of medical care practice, and into what actually happens at the interface of processes of diagnosing and prognostication, and of establishing facts and values. There is a need for this type of study because it is precisely the established routines and practices of actual medical intervention that are constantly destabilized in a health care system that is primarily marked by rapid change. The ensuing uncertainties have contributed to the emergence of a 'grey area', one where the established protocols and the conventional answers found in medical handbooks no longer apply. Yet, as before, many clinical conditions still require immediate medical attention and intervention. […] How do the staff members deal with the uncertainties that are intrinsic to being on a scientific-medical frontier? […]

Aside from the ongoing need to develop pragmatic guidelines, the complex problems of our high-tech health care have to be addressed in other ways. It is argued that although various aspects of the contemporary neonatal practice have been studied thoroughly, there is still little insight into the hidden competence of the actors involved to cope with the complicated interplay of problems and dilemmas associated with the actual processes of managing day-to-day operations in the NICU. Mostly a NICU appears to be a smooth, well-ordered practice with professionals who know what they are doing and who treat and care for children in a routine manner. Yet appearances are deceptive: the order has to be *made* and adjusted constantly because in the treatment of gravely ill, unstable newborns the existing rules and routines will not always be effective for addressing new and unexpected situations. In a NICU, the normal everyday practice tends to be the outcome of a deliberate ordering process that leads a fragile existence. After all, there are the children who do not always respond to medical interventions as foreseen or for whom normal values are not even available yet. Furthermore, frequently decisions have to be taken within a very short time span and in the absence of—reliable—factual data. No wonder that occasionally intervention processes falter and, in the worst cases, end in a deadlock. To create, reproduce, and uphold the social-technical order in today's medical practice calls for a substantial effort on the part of those involved. This effort is the object of analysis in

this book. Its focus is on the interplay of control and contingency in critical care units like a NICU. Therefore, this book should not be viewed as strictly an inductive effort, or as just another case study. Instead, its analytical scope and effort can be understood as an act of *exnovation.*

Exnovation refers to the attempt to foreground what is already present—though hidden—in specific practices, to render explicit what is implicit in them (de Wilde 2000). Where innovation can be defined as 'to make something new', exnovation pays attention to what is already in place and challenges the dominant trend to discard existing practices (p. 13). Importantly, 'things or practices are not less valuable simply because they already exist' (p. 13). A focus on exnovation allows us to bring to light implicit matters of actual practice and to develop a fresh perspective on the ingenuity of the professionals and the specific structure of their practices. Exnovation offers insights into their specific modes of ordering day-to-day practices (Law 1994). Exnovation, in other words, elucidates competencies of coordination and alignment of these modes of ordering of which those involved are not always aware.

From: Chapter 2, Newly Born and Indeterminate, pp. 36–38, 45

Styles of Reasoning

By removing technology support, such as artificial ventilation, preterm infants die within minutes to hours. […] Although each month one member of the team of neonatologists is formally in charge, in Dutch hospitals these kinds of difficult decisions are taken collectively by the entire team. The medical staff of the Academic Medical Center NICU consists of neonatologists and if needed other medical specialists.

In the staff meeting all data is re-ordered again. Various methods are used to do so. This ordering process can be described on the basis of the notion of 'repertoire.' A repertoire involves a particular style of reasoning; as such it functions as a guiding principle that orders our ideas about what the world is and how it works. This guiding aspect should not be viewed too strictly, though. Rather than exactly fixing what will be said

or done, a repertoire determines what those involved view as relevant, which arguments or strategies, they feel, matter. It outlines what is central or peripheral in a particular situation of condition. It provides a frame for legitimizing decisions.

> 13.30 hours: The staff meeting begins. Its subject is the proposal to refrain from further treatment in the case of Esther. Seven staff members are present: the attending neonatologist, the resident on duty, two nurses who provide care to Esther, two other neonatologists, and a social worker.
> The resident opens the meeting with a report on the course of Esther's condition since her birth and her current condition. She concludes her introduction with the question: 'In light of the problems and taking into account the child's immediate future and her very bad prognosis, what is our policy going to be?'
> 'What is "very bad"?' the social worker wants to know from the resident.
> 'A fourth-degree bleeding at both sides of the head makes her chance of survival very small and if she survives at all, what kind of life are we then talking about?'
> 'What do the parents think?' one of the nurses asks.
> The resident: 'If their child is going to be severely handicapped, they do not want us to keep going on.'
> The social worker, who also talked to the parents, reports: 'They do not regret their decision to have Esther treated, but they do have second thoughts if their child will be seriously handicapped. They told me: "It is something with which we want to burden neither the child nor ourselves." In fact, based on the information they so far received they have already concluded for themselves that they have to reckon with their child's passing. This is why at any rate they would like to have their child baptized. It might still be done today.'

In the first ten minutes of the meeting all staff members who in the past few days could constantly be found near Esther's incubator articulated their concerns and points of view. Their stories suggest that they all use a repertoire in which the child's specific situation is center stage. These speakers mainly rely on a situational repertoire. In this style of reasoning the uniqueness of a situation is foregrounded, situating the issue involved—the child in this case—in the here and now. Explicitly the

child is associated with specific persons, places, and moments, and thus individualized. […]

Next, the discussion takes a turn, when the two neonatologists who are not directly involved in Esther's treatment join in and challenge all that has been said so far.

> One of the neonatologists: 'Has an EEG been made as well?'
> The resident: 'No EEG was made. If you think it is useful for determining our course of action, we should have one made. But what are the criteria you use when the results come back?'
> The neonatologist: 'I believe that with a normal EEG you cannot make a life-ending decision.'
> 'Do you really think,' the resident asks, 'that with this cerebral condition there is a chance of getting a normal EEG? Don't get me wrong, I only try to explore the boundaries of the new parameters on which to base our policy.'

Unlike the actors directly involved, these two neonatologists are not yet fully convinced of the hopelessness of Esther's situation. They do not only present another opinion, however, but also introduce another style of reasoning: a case repertoire. In this logic the child is specifically considered in relation to other, similar cases. Thus, this repertoire reaches beyond the boundaries of the specific situation of the child at hand by inserting the outside world. The meeting no longer only addresses Esther, but also criteria for assessing an EEG result, parameters that help to determine the course of action, and anonymous children that are described as statistical units in the literature. The case repertoire allows one to highlight other aspects of a child's identity, thus breaking the dichotomy between the general case and the specific child. Esther too is a case.

….

An answer to the question 'what to do?' is closely intertwined with the question 'what is the matter here?' A reply to this question requires more than just a simple establishing of the facts. In a NICU facts are not so

much givens, but they are moulded and fashioned on the basis of various materials, such as words, numbers, actions, and things. The staff is constantly geared toward collecting data to determine a child's situation. Thus the child develops from a 'case' into a child with its own identity. Yet more is going on. In the effort needed to do away with the child's unspecified identity, the NICU itself takes shape as a practice. In this process repertoires are deployed, brushed aside or combined. Their value or use is neither fixed, nor do they coincide with a specific discipline, a systematic treatment trajectory or a specific argument.

From: Chapter 4, Uncertain Trajectories, pp. 113–114

The NICU as a Quantitative Practice

By constantly gathering numbers, calculating ratios and quantities, entering quantitative data on special forms and classifying them, and by interacting with each other in numeric language, the staff is able to monitor the condition of the child. Numbers, however, do not speak for themselves, nor can a large flow of quantitative data do away with each and every uncertainty: medical intervention trajectories in the NICU are always rife with risks and uncertainties. As tools, quantitative input and output are constructed in their actual application in practice. This contributes to a *tension* between contradictory numerical frameworks. On the one hand, numbers are considered as objective reflections of *reality*; on the other hand, they are constitutive elements of this same reality.

In other words, numbers do not possess a solidity of their own, but become facts through *processes of negotiation*. Although claiming and seeming to rely on the exactness and objectivity of digital data, the staff engages in continuous negotiations about their meaning. A closer look at their daily activities reveals the contextual reframing of numbers. Knowledge derived from hard numbers cannot be applied irrespective of their context. There are always situation-specific activities and decisions. They are related to other numbers within particular contexts of practice and meaning. However, the existence and knowledge of such a framework is no guarantee that medical decisions and interventions will proceed smoothly. The distribution of numeric certainty and credibility

appears not to be arbitrary but is rather affected by contextual constraints and possibilities. Again, there can be a mutual confirmation of numbers or continuing struggles for credibility. Analysis of this contingent interaction shows how the meaning of numbers in terms of true or false or certain or meaningless, is the outcome of a distribution of credibility within a network of quantitative data and other frames of knowledge. As such, the meaning of numbers is shaped by specific contexts.

From: Chapter 5, Beacons on the Horizon, pp. 124–125, 136–137

A Topography of Experience

All actors in the NICU find themselves in a dynamic of experience and expectation that allows them to form and articulate a prognosis about a child. This not only applies to knowledge that is tied to education and position, but also to knowledge gained through all sorts of personal experiences involving the child and other NICU actors. In the specific ways in which nurses relate to a child—how they approach him, what they know about him, what they feel for him, how they speak for him—the subjective knowledge and experience emerge that are also used in prognoses. In other words, study of how those involved relate to Tom may concentrate on issues of role distribution and position, including the associated knowledge and prognosis, and on issues tied to the individual dimension of dealings and interactions with the child. Aside from professional knowledge, which generally emerges based on training, professional literature and deliberation, there is also knowledge and/or experience based on *contact* with the child and others involved. By focusing on this interactive dimension, room emerges in the analysis for the *individuality* of those involved as well as for other factors that play a role in the formulation of the prognosis, such as temporal aspects of specific situations and emotions like hope and frustration. The ways in which actors deal with children in the NICU can be conceptualized in terms of distance versus proximity, observing versus comparing, and hands-on versus hands-off.

…

Prognostic Markers

Prognoses, then, are the outcome of multifaceted prognostic *processes* that reflect a certain amount of conflict and disparity between the experience and expectation of the actors involved. They all deploy experiences from the (recent) past to interpret both the developments that occur along the trajectory and—by extrapolation—the ones that are likely to occur in the near future. This gives rise to specific 'horizons of expectation', whereby the measure in which expectations are realized plays a palpable role as well (Koselleck 1985). In their formulation of new expectations, actors rely on subsequent knowledge. This may cause them to adjust their prognosis in a specific direction. It is in the reflection on the past that the future takes on a specific significance. Thus prognostic processes involve a linking of past and future in the present, resulting in a 'current past' and a 'present future.' In other words, a multi-layered understanding of such prognostic processes requires an exploration of the boundaries of the 'space of experience' of those involved and the way in which these boundaries shift. […]

In a NICU various prognostic markers are used to determine a child's prognosis. Their analysis may reveal the ways in which individual experience and the dynamic of the treatment trajectory (including the learning processes among those involved) influence the various prognostic processes. A number of reference points play a major role: other children that serve as an exemplary case, the level of technological support on which the child depends, the use of the NICU space or the specific pace and rhythm of the care and the treatment provided. They can be said to function as *prognostic markers*, on the basis of which those involved conceptualize the child's position along the treatment trajectory.

From: Chapter 7, The End of the Journey, pp. 187–190

Opening up the In-between Zone

By opening up the interface between diagnostic processes and processes of prognostication; the general and the particular; actors and technologies; formal protocols and the swirl of the treatment trajectory; public

and local accountability; facts and values; expectation and experience, it becomes clear that good intentions and a gamut of data and guidelines can never fully preclude problems from occurring. In the treatment of children in the NICU there is always a marked tension between the familiar and the unusual, control and contingency, certainty and doubt, cohesion and conflict. In some cases the knowledge or technologies needed may simply not be available. But even if they are, it is not yet taken for granted which knowledge or experience matters or which technology is effective. Time and again, the value of the available knowledge has to be weighed, or it has to be decided which guidelines apply or which perspective is most valuable. These aspects are always, directly or indirectly, objects of negotiation.

To keep complex treatment processes going more appears needed than merely the presence of knowledge, experience, and technology. Their application is not automatic but requires active involvement from doctors, nurses and parents. My analytical focus on the in-between zone—on the hinge between the known and the unknown, the risk and responsibility, and the collective and the individual—enables me to exnovate an available yet hidden form of competence that allows the staff to prevent the treatment process from stalling. One of the key insights of this book is the identification of the *coordination* between the individual, collective and systemic resources that are used to enhance the staff's competence to produce workable knowledge and reliable performance while acting within a complex critical care unit such as a NICU. […]

It turns out that in addition to the more tangible and concrete actions and interventions of the NICU staff members, more abstract processes are at work as well, and prominently so. Specifically, various styles of arranging and interpretation play a major role in decisions on treatment: repertoires guide processes of reasoning and legitimating, vocabularies suggest ways of speaking and interpreting, and scripts imply more or less explicit directions for action. Their application is not automatic but requires active involvement from doctors, nurses and parents. Exnovating the competence of staff members to select and combine the different styles of ordering provides insights into the way they actually deploy their knowledge, experience, and technology in the treatment trajectory.

…

The performative character of the various ways of ordering gives direction to how the treatment process takes shape. This may lead to frictions in the decision process regarding responsibility, the timing of when something has to be done, or when enough is really enough. To resolve such frictions, the actors look for a way out by combining vocabularies: they speak in terms of 'compelling advice'; they in part move away from the script and add elements to a treatment guideline; they combine repertoires or merely opt for a confirmation of the radiological report. The various styles of reasoning, therefore, will rarely be encountered in their pure form. This is why the situating of knowledge and morality requires coordination not only at the level of the individual case (the construction of facts, the robustness of a moral turning point or the choice of a treatment trajectory), but also at the level of repertoires, vocabularies and scripts. Securing the treatment trajectory's progress calls for coordination at the level of the individual case as well as at a meta-level. To foreground these acts of coordination offers not only a new perspective on the competence of the actors involved, but also on the ordering character of reasoning, speaking, and acting.

Reflection by Jessica Mesman

Uncertainty in Medical Innovation aims to answer the question how healthcare staff succeed in acting promptly and adequately in situations of medical and ethical uncertainty. Diagnostic and prognostic facts are vital in their decision-making process, while at the same time these facts are hard to establish in a high-density zone of doubt, like an intensive care unit. In order to identify ways of knowledge production the book has its focus on the in-between zones, like for example the intersection of the general and the particular; protocols and the swirl of the treatment trajectory; facts and values; expectation and experience. This analytical emphasis on gradualisation (alignment, fine-tuning) rather than using a comparative/contrastive approach (e.g. the individual or the collective; certainty versus doubt) made me aware of the importance of implicit coordinative methods and strategies to order types of actions, styles of reasoning and forms of interaction. Whereas protocols and guidelines are

petrified experiences that capture the anticipated, the coordinative competences of staff deal with what is left to practices in the situation at hand.

My analysis exnovated the presence of the staff's coordinative competences that helps them to navigate in an often, uncharted territory. Moreover, it also made me aware that the significance of such competences is highly underestimated. They are hardly ever discussed, let alone being included in medical curricula. As an act of signification in which staff build an understanding of an event, these coordinative competences are vital for achieving a reliable and professional outcome in any practice and therefore deserve attention. Moreover, I realised that insights in these unarticulated actions also provide opportunities for improvement.

Whereas the responses by medical practitioners to my book had been very positive, it had not resulted in any practice improvement. Although it had never been my aim, it did frustrate me. From that moment onwards my exnovative quest became to foreground the ingenuity of practitioners in order to gain insights and to contribute to practice optimisation.

During this time the issue of patient safety was high (and still is) on the agenda of healthcare. Aiming for practice improvement made patient safety an obvious choice. Not being trained as safety officer, my research question became again a positive one: 'how to accomplish and preserve safety despite the complexities of everyday practice?' It turned out that this positive approach made me an outsider in the world of patient safety for many years as at that time everyone else in this area (including its funding) had their focus on causes of errors and incidents.

Based on my study in the neonatal intensive care unit I was aware how the ordinary is actually an extraordinary accomplishment. I therefore turned my analytical focus to the 'mundane' in order to excavate the hidden competences that contribute to patient safety. However, how to recognise and learn from practices that are used so often that they have become invisible or even forgotten. Fortunately, my book won the *Sociology of Health and Illness* Book of the Year Prize. This award generated publicity that reached as far as Australia. Based in Sydney, Rick Iedema, Katherine Carroll and colleagues studied the habitus of healthcare professionals with the help of video-reflexive ethnography (VRE). VRE is a collaborative method that involves filming daily practices and

showing selected clips back to the participating professionals who—together with the researcher—conduct the analysis. The outcome of these reflexive meetings acts as a basis for academic output as well as practice improvement. The notion of 'exnovation' was a perfect fit with VRE as being a bottom-up approach, as it captures the idea of 'innovation-from-within'. For me, on the other hand, VRE was the key I was looking for to open up mundane practices. Rick, Katherine, and I became friends for life and co-authors of several publications (e.g. Iedema et al. 2013). In our collaboration the video-reflexive method matured and diversified (Carroll and Mesman 2018). Over the years 'exnovation' has been further developed by the VRE-community and now acts as one of the four guiding principles of VRE (Iedema et al. 2019). That the VRE method provides an excellent infrastructure for practice optimisation is also recognised by several organisations in healthcare (like the Mayo Clinic and the International Red Cross), education, and infrastructure (railway). Several projects took off, are done or are still running (Mesman and Carroll forthcoming).

In the meantime, the world changed. Academia adopted 'societal relevancy' as an important criterium for the evaluation of scholarly work. Now my work is evaluated from another perspective. The world of patient safety turned towards a positive approach. This too re-positioned my work and expertise. Many practitioners are fed up with innovations from outside and want to take control over their own work and its improvement. VRE offers them a tool to do so. Together with others I train them how to use the method and leave happily. Empowerment-in-action is what stays.

It started with the book. Then, on the high wave of the FSHI Book prize, 'exnovation' started to travel to Australia, teamed up with the VRE method and continued its travel to the US, the UK and beyond. The book, the prize, Australia, societal impact, the positive approach in patient safety … too good to be true? Some people are just lucky, while others are persistent in their quest and wait patiently for the right moment! I might be both.